

# LB1256: New findings from the 2020 MS Barometer on MS prevalence, practicing neurologists and use of disease-modifying drugs across Europe

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# Disclosures

C.H. Whicher, T. Albone, A. Taylor, D. Ratchford and C. Merkel have no conflicts of interest to disclose.

N. Kriauzaitė and E. Kasilingam have no personal pecuniary interests to disclose. Their organization, the European Multiple Sclerosis Platform (EMSP), receives grants and sponsorships from Actelion, Almirall, Biogen, Bristol Myers Squibb, icometrix, MedDay, Merck, Mylan, Novartis, Roche, Sanofi Genzyme and Teva.

# Background

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The European Multiple Sclerosis Platform (EMSP) has conducted a survey of national multiple sclerosis (MS) societies periodically since 2008. The 'Barometer' assesses the performance of health and social care systems using national data and knowledge. It aims to provide an accurate picture of MS management across Europe and support international benchmarking.

Previous iterations of the Barometer have supported evidence-based policy development and improvements in access to treatment, care and quality of life for people with MS.

Preliminary findings for 3 of 76 questions are presented in this poster. The full 2020 MS Barometer will be launched in December 2020.

# Objectives

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To carry out a sub-analysis of the Barometer findings on:

- the number of people living with MS in Europe
- the number of practicing neurologists
- the percentage of people with MS on disease-modifying drugs (DMDs).

# Methods

## Surveyed countries:

Austria, Belarus, Belgium, Bosnia and Herzegovina, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Moldova, the Netherlands, North Macedonia, Norway, Poland, Portugal, Romania, Russian Federation, Serbia, Slovenia, Spain, Sweden, Switzerland, Turkey and the United Kingdom.

The Barometer questionnaire was developed in consultation with an expert group composed of representatives from national MS societies, healthcare professionals, industry and the Copenhagen Institute for Future Studies. It was distributed via SurveyMonkey to all member societies of EMSP.

Of the 76 questions in the survey, this poster presents responses for:

- What is the estimated total number of people living with MS in your country?
- What is the number of practicing neurologists in your country?
- What percentage of the total population of people diagnosed with MS has received DMD treatment in your country in 2018?

Prevalence was calculated using 2019 population data from the United Nations Department of Economic and Social Affairs.<sup>1</sup> For all questions related to DMDs, respondents were asked to consider the following treatments: interferon-beta 1a, peginterferon-beta 1a, interferon-beta 1b, glatiramer acetate, teriflunomide, dimethyl fumarate, fingolimod, cladribine (oral), siponimod, natalizumab, alemtuzumab and ocrelizumab.

Data were collected between September 2019 and July 2020. The survey results were examined and clarified as necessary with the relevant national society.

Throughout this poster presentation, we refer to our findings as applying to 'Europe' or 'the European region', which we define as encompassing all surveyed countries.

1. United Nations Department of Economic and Social Affairs. 2019. Population Data. Standard Projections (Estimates and Projection variants).

# Results: What is the estimated total number of people living with MS in your country?

An estimated 1,130,685 people live with MS across 35 European countries

Country	People with MS	Prevalence per 100,000	Country	People with MS	Prevalence per 100,000	Country	People with MS	Prevalence per 100,000
Austria	13,500	151	Hungary	8,500	88	Poland	50,000	132
Belarus	4,600	49	Iceland	720	212	Portugal	8,364	82
Belgium	13,500	117	Ireland	9,000	184	Romania	9,000	46
Bosnia and Herzegovina	3,557	108	Italy	126,000	208	Russian Federation	92,500	63
Croatia	6,000	145	Latvia	2,035	107	Serbia	9,000	103
Czech Republic	20,000	187	Lithuania	3,000	109	Slovenia	3,500	168
Denmark	16,169	280	Luxembourg	700	114	Spain	55,000	118
Estonia	1,000	75	Malta	400	91	Sweden	21,500	214
Finland	12,080	218	Moldova	1,500	37	Switzerland	15,000	175
France	115,000	177	The Netherlands	25,000	146	Turkey	70,000	84
Germany	250,000	299	North Macedonia	1,560	75	United Kingdom	130,000	193
Greece	20,000	191	Norway	13,000	242			

# Results: What is the number of practicing neurologists in your country?

33 countries reported a total of 61,002 practicing neurologists, a median of 1 per 23 people with MS

Country	Number of neurologists	Ratio of people with MS to neurologists	Country	Number of neurologists	Ratio of people with MS to neurologists	Country	Number of neurologists	Ratio of people with MS to neurologists
Austria	800	17:1	Hungary	500	17:1	Poland	2,320	22:1
Belarus	No response	-	Iceland	24	30:1	Portugal	230	36:1
Belgium	634	21:1	Ireland	32	281:1	Romania	800	11:1
Bosnia and Herzegovina	150	24:1	Italy	3,000	42:1	Russian Federation	28,600	3:1
Croatia	No response	-	Latvia	242	8:1	Serbia	450	20:1
Czech Republic	1,264	16:1	Lithuania	400	8:1	Slovenia	150	23:1
Denmark	308	52:1	Luxembourg	37	19:1	Spain	3,100	18:1
Estonia	20	50:1	Malta	7	57:1	Sweden	450	48:1
Finland	347	35:1	Moldova	254	6:1	Switzerland	623	24:1
France	2,648	43:1	The Netherlands	839	30:1	Turkey	3,000	23:1
Germany	7,537	33:1	North Macedonia	136	11:1	United Kingdom	880	148:1
Greece	500	40:1	Norway	720	18:1			

# Results: What percentage of the total population of people diagnosed with MS has received DMD treatment in your country in 2018?

30 countries reported on people with MS on DMDs: a European median of 51%

Country	% DMD use
Austria	65%
Belarus	No response
Belgium	70%
Bosnia and Herzegovina	10%
Croatia	32%
Czech Republic	82%
Denmark	48%
Estonia	50%
Finland	43%
France	80%
Germany	76%
Greece	70%

Country	% DMD use
Hungary	47%
Iceland	No response
Ireland	50%
Italy	51%
Latvia	No response
Lithuania	90%
Luxembourg	No response
Malta	90%
Moldova	6%
The Netherlands	No response
North Macedonia	37%
Norway	50%

Country	% DMD use
Poland	30%
Portugal	82%
Romania	67%
Russian Federation	30%
Serbia	12%
Slovenia	70%
Spain	78%
Sweden	51%
Switzerland	90%
Turkey	65%
United Kingdom	32%

# Discussion

The MS Barometer survey has shown that MS affects over 1.1 million people in Europe. The observed variability in the prevalence of MS across different European countries may in part be explained by inadequate detection, as well as challenges with data collection in countries that do not have an MS registry.

61,000 practicing neurologists were reported across 33 countries, resulting in a median of 1 practicing neurologist for every 23 people with MS. However, there was significant geographic variation – the highest ratio (Ireland at 281:1) was nearly 100 times the lowest.

Neurologists play a key role at all stages of MS management. A high ratio of people with MS to neurologists would suggest unacceptable delays to diagnosis and inadequate access to care. This measure does not consider any non-MS commitments the neurologist may have; therefore, the shortage of access to neurological care may be more severe than our figures suggest.



# Discussion

A median of 51% of people with MS in Europe were reported to receive DMDs in 2018. Of the 30 countries which responded to this question, the percentage ranged from 6% in Moldova to 90% in Lithuania, Malta and Switzerland.

Prompt initiation of DMDs is critical to slowing disease progression, as well as supporting quality of life and independence for people with MS. These suboptimal and variable DMD treatment rates indicate that people with MS face significant barriers to accessing essential therapies. One reason for this may be the shortage of neurologists, who are typically responsible for initiating and overseeing DMD treatment. The situation may also reflect wider access challenges, including reimbursement barriers, delays to approving new medications or limitations to prescriptions. The full 2020 MS Barometer will explore these challenges in greater detail.

The data are limited by the observational nature of the survey. Some national societies have drawn upon MS registries, while others provided a best estimate. We are unable to account for responses to certain questions; for example, the reported prevalence of MS in Hungary is lower than in 2013.<sup>2</sup>

# Conclusions

The MS Barometer aims to support improvements in access to high-quality treatment and care across Europe through international benchmarking and data-driven advocacy. These preliminary findings from the 2020 MS Barometer provide an updated figure for the number of people living with MS in Europe and indicate that significant geographic disparities persist in the clinical management of MS. Sub-optimal management of MS, of course, leads to worse health outcomes. The subsequent increase in health and social care needs will have wider repercussions for family members and informal carers, as well as wider social impacts due to lower workforce participation. We hope that these new data can help drive policy change, ensuring that all people with MS are able to access optimal care and support regardless of where they live.